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ABSTRACT

This paper presents an analysis of current education services for students with traumatic brain injury (TBI) from the perspectives of children, parents, and educators. It presents results from several pilot surveys that asked parents and educators to identify the strengths and weaknesses of current educational services for students. Guidelines for helping parents to effectively negotiate the school system are offered. The survey of 31 parents of children with TBI found that parents were dissatisfied with their child's school in five of six domains (only physical accessibility was rated positively). Parents identified limited staff knowledge of TBI and limited resources as the primary reasons for the school's unsatisfactory performance. In two surveys, educators (N=183 and N=34) attributed their own lack of knowledge and the cognitive deficits of students as barriers to TBI students' successful school experiences. An inverse relationship between the educator's level of knowledge and perceived competence was also found. Three guidelines for parents are presented: (1) become informed about services that will help your child and about your rights in accessing these services; (2) establish a collaborative relationship with the education team; and (3) remember to take care of yourself to help cope more effectively with stress factors. (Contains 29 references.) (DB)

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Helping Parents Negotiate the School System

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Helping Parents Negotiate the School System

Once a child returns to school following a brain injury, the educational system becomes the primary service provider for that child (Savage & Wolcott, 1994; Ylvisaker, Hartwick, & Stevens, 1991). Because most children and adolescents make excellent physical recoveries after brain injuries, it has been assumed that their return to school would be relatively smooth (Lehr, 1990), and that their educational needs could be addressed by existing regular and special education practices. It is only recently that medical and school personnel have realized that many students experience a range of unique challenges when they return to school.

An increasing number of articles in the past several years have been devoted to effective educational programming for students with ABI. Authors have offered detailed guidelines in the following areas: evaluation (Begali, 1994; Savage & Carter 91), placement (Cooley & Singer, 1991; Savage & Carter, 1991); transition from hospital to school (Savage & Carter 91; Lehr, 90; Savage, 91; Ylvisaker, Hartwick, & Stevens, 1991); modifying educational environments (Blosser & DePompei, 1994; Cohen, Joyce, Rhoades, & Welks, 85; Cohen, 91) specific instructional and behavioral strategies (Blosser & DePompei, 1994; Cohen, 1991; Glang, Singer, Cooley, & Tish, 1992; Deaton, 1994; Light, Neumann, Lewis, Morecki-Oberg, Asarnow, & Satz, 1987; Savage & Wolcott, 1988) and transition to post-high school education and employment (Nordlund, 1994, Condeluci, 1994).

The success of the school experience for most children may depend not only on the strategies employed in the school setting, but on the advocacy skills of their parents. Parents who are knowledgeable about the kinds of services and approaches that can help their child, and who effectively advocate for them will be more satisfied with their child's educational program (see Lash, this volume). As one mother said:

> I don't know if my son's school ever had students with traumatic brain injury..Because I was an educator, because I am an advocate for my child, I think I forced them to look at the issue. But, most people wouldn't go through what we went through...We became the clanging bell...the parents that they could never please.

The purpose of this chapter is to present an analysis of current educational services for students with TBI from the eyes of those who have most at stake in the success of these services: children, parents and educators. This chapter will present results from several pilot surveys that asked parents and educators to identify the strengths and weaknesses of current educational services for students. Information gathered from qualitative interviews and participant observation will expand on the survey results. Guidelines for addressing some of the key challenges identified and helping parents effectively negotiate the school system to achieve successful school experiences for their children will be offered.

The Challenge of ABI: Child, Parent, and Educator Perspectives

Developing an effective educational program for a student with ABI presents a challenge for everyone involved. At the center of the challenge is the child or adolescent, who returns to school as a different person, with changes in nearly every aspect of his or her life. Each child or adolescent experiences differing cognitive, behavioral, physical, and emotional alterations as a result of brain injury; the effects of these changes will produce life-long changes in the child's self-concept. For example, one adolescent talks about how the effects of his injury affected his career plans:

> I've always known I was going to go to college. I didn't know what I was going to do....After my head injury, a lot of my problem solving and cognitive (abilities)....for English and spelling..and that basic core curriculum--that was a lot harder for me, so I didn't enjoy it anymore. So that kind of eliminated that area of career choice....but one thing that wasn't really hampered was creative ability. .... That's what I was left with, so I kept working with it and now I love it, so....that's why I'm planning on going into it.

Almost all children and adolescents will also notice dramatic shifts in their social support network (see Singer & Nixon, this volume; Thomsen, 1974; Willer, Allen, Durnan & Ferry, 1990). As one adolescent reports:

> It's like my life had changed after my head injury...it was real hard to deal with people that were used to me being a different way than I was. And, there were things that they expected that I couldn't do...I wasn't in a

wheelchair...and I didn't have scars on my head...(so) they couldn't see that I had some real disabilities.

Social isolation can become more extreme over time, as students with TBI miss out on opportunities to learn age-appropriate social skills and therefore engage in social behaviors that their peers find bizarre or offensive. The following description from a series of participant observations illustrates this problem.

At age 13, six years after his head injury, Mike became interested in girls. At first his interest was manifested by staring intently at certain girls in classrooms and between classes, Later, observing the behavior of his peers, Mike started making sexually suggestive comments as girls walked by. However, unlike his peers comments, Mike's comments were audible to the girls. Mike also repeatedly sent friends o tell a girl that he wanted to go out with her, much to the girl's embarrassment. In one class he continually whispered to the girl sitting in front of him, "Let's do it!. Want to do it with me? When can we do it?" The girl found his remarks threatening and offensive and complained in tears to the teacher about Mike's behavior.

Not only are children coping with the many changes resulting from injury, but this process of improvement following brain injury is superimposed on the overall process of child development (see Lehr , this volume). The dual-pronged nature of the rehabilitation process can be particularly problematic for adolescents. The cognitive, behavioral, and social challenges they face are exacerbated by the increased demands of secondary settings (Ewing-Cobbs, Fletcher, & Levin, 1985; Rosen & Gerring, 1986). Students must operate in larger schools with more complex scheduling and more difficult logistical demands. There are also more peers to interact with, at a time when all students face the dramatic developmental changes and insecurities of adolescence. Most importantly, students with TBI are expected to function more <u>independently</u> in these new and complex environments. As students transition to middle and high school settings, not only must they manage the complicated details of this demanding environment, they must also demonstrate that they are developing skills necessary for adulthood: learning to solve problems on their own, and to

handle the frustrations of this difficult time with decreasing assistance from adults.

Educator's perspective. For the educator, the student with ABI presents a complex constellation of needs. Most educators have not received training in acquired brain injury (Savage, 1985) and feel unprepared to meet these students' needs (Cooley & Glang, 1994; Savage & Carter, 1991). Moreover, the heterogeneity of the TBI population makes these students particularly challenging for general educators; no one approach, strategy, or curriculum is appropriate for all students in this group (Cooley & Singer, 1991). Reflecting on her year-long experiences with a particularly challenging student one teacher said:

> He's the only identified child with TBI we had...and we didn't know what to do with him.

Lack of awareness of the range of effects of TBI and how these might be manifested in student behavior also contributes to educators' difficulty in meeting student needs. A teacher who struggled with the severe behavior problems of one of her students reported:

> I called his mother recently. As it turns out, he had a severe head injury five years ago and maybe that has something to do with it, I don't know. His mother explained that these episodes are usually set off by stress and a warning sign that he's going to have a tantrum is that he gets a severe headache. Well, I never put any stress on him. I have the same expectations for him that I have for all my other students. Besides, once he said he had a headache, but when I sent him to the nurse, boom, within two minutes he was playing with another boy that was down there. I'm not buying the head injury aspect, I think he's just trying to get out of doing his work.

Parents' response. Parents encounter an on-going source of stress when their child returns to school. In addition to the financial and emotional burdens involved with coping with ABI, parents now face the added stress of working with school professionals (who may or may not be knowledgeable about brain injury) to access needed educational services for their child. Because prior to the

injury most children with ABI progressed normally through school, parents may be unfamiliar with their rights under the Individuals with Disabilities Education Act of 1990 (PL 101-476) , and many find the system unwieldy. In addition, parents may find that schools can provide a much lower level of services than was provided in the rehabilitation setting, particularly in the areas of physical, occupational, and speech therapies (Lash & Scarpino, 1993). As a result, parents may make what appear to be unrealistic demands for services, which can cause a defensive response by school personnel, and sets an adversarial tone for parent-professional interactions.

Unfortunately, parents are forced to become an advocate for their child at a point when parents are overloaded and ill-prepared to become involved in such a complicated process (Savage & Carter, 1991). As one parent reports, her first encounters with the educational system came at a very stressful time:

> ....all of our efforts had been in trying to keep the rest of the family healthy, trying to keep our marriage alive....

Another parent began her role as advocate following a car accident in which her husband was killed, both of her children sustained head injuries, and she herself was injured.

The stresses parents must cope with do not diminish once the child or adolescent has successfully transitioned to school. At the beginning of each new school year (and in many cases, the beginning of each new school term), the child and parents must learn how to negotiate a new schedule, become familiar with new teachers' classroom systems, and learn to work collaboratively with a new group of professionals. In reality, then, the transition to school really does not fully end until the child has left the public school system.

Parents who are strong advocates for particular services for their children are sometimes labeled by school personnel as being "in denial" about the severity of their students' cognitive disabilities or inappropriate behaviors. When asked how she handled such negative perceptions, one mother, who had adopted 10 children with head injuries said:

> I begin every meeting with a new school representative by saying, 'Everything you've heard about me is true: I'm in denial, I'm a crazy lady, I'm unrealistic. Now, let's get down to business.'

Another mother who felt responsible for the accident that caused her daughter's head injury in infancy said:

> I finally sat all the school people down and said, 'Look, I'm motivated by guilt, and you should know that because of that, I'm not going to stop hounding you until give my daughter the services she needs.'

Pilot Surveys

A range of problems with the way schools serve students with ABI have been identified in the literature (e.g., Cooley & Singer, 1991). In an attempt to ascertain parent and teacher perspectives of current educational services, two pilot surveys and a series of focus groups and qualitative interviews were conducted.

Parent survey. In the fall of 1993, 31 parents throughout the northwest completed a questionnaire about their child's educational experiences. All but 2 of the parents had a child who had survived a traumatic brain injury more than 2 years prior to completing the survey (the children of the remaining 2 parents were more recently injured). The children ranged in age from 5 - 21. Six of the children were currently served in inclusive settings with non-handicapped peers; 15 were placed in self contained or pull-out programs; and the remaining students were no longer attending public school.

All of the parents felt that brain injury had significantly impacted their child's educational experiences. The parents identified problems with organization and planning, memory, behavior, and social isolation as barriers to successful experiences.

Most of the parents were dissatisfied with how well the school addressed their child's educational needs. Table 1 shows how parents rated the schools attended by their children in six domains. The only domain where parents felt schools were doing a satisfactory job was in making the school physically accessible; in all 5 of the other domains, parents rated schools as doing a less than satisfactory to poor job.

Table 1 Parent's rating of school's performance in 6 educational domains (N = 26)

1 School does a poor job		5 School does a great job
	Mean rating	SD
Making the school physically accessible	4.15	.89
Training teachers to understand TBI	1.89	1.14
Dealing with social and behavioral problems	2.16	1.27
Dealing with memory and learning problems	2.4	1.2
Helping child/adolescent become independent	2.8	1.2
Communicating with family about coping with TBI	1.92	1.14

The respondents identified 2 key reasons for the school's unsatisfactory performance--limited staff knowledge of TBI and its related effects (46%), and limited resources (24%). When asked what they might recommend to their child's school to improve services for students with TBI, 15 of the parents recommended more training for teachers and related service staff serving students with TBI. A number of the parents suggested that schools improve communication with parents. Parents commented that schools would be more

successful in designing educational programs if they worked more closely with parents. For example, one parent wrote:

> (Schools should) communicate more with the child's parents, and consider the parents to be the child's key link between the child's educational experience. (They should) listen to parents, they do know their child.

To further explore parent perspectives, a focus group was conducted with a sample of parents who had responded to the survey. In the focus group, parents consistently reported feeling frustrated with their children's school experiences. This occurred in spite of the fact their children were quite diverse, representing a variety of ages, etiologies, levels of functioning and time post injury. As described by the parents, the obstacles to successful school experiences could be classified into four categories: 1) educational barriers produced by the child's memory/organizational impairments, 2) problems due to students' poor social integration, 3) difficulties produced by teachers' misperceptions about brain injury, and 4) frustrations related to schools' inability to adjust their regimen to the needs of the student.

Several parents made comments about a particular teacher or administrator who demonstrated a caring attitude; however, there were virtually no descriptions of positive actions taken by a school or classroom teacher that resulted in more effective educational experiences. The parents themselves had generated and shared with teachers many helpful strategies, but for the most part, these were not implemented in the school settings. For example, one parent described the importance of her son taking a short break when he felt overwhelmed by too much information. This strategy had been quite effective during her son's therapy sessions in the medical setting. When this idea was posed to her son's teacher, it was rejected as the teacher felt it might set an undesirable precedent for other students. Other representative comments from parents include:

> His teachers tended to only focus on the fact he had previous behavior problems and didn't recognize the contribution of the head injury

> Every day is different for my child depending upon his fatigue, stress, etc.--when he performs differently in different classes they think he isn't trying

> The principal said the regular teachers in the 6th grade did not want to do the extra stuff for my son so that we should wait till the 7th grade when there were some teachers who were more supportive of handicapped kids

Educator surveys. The results from the parent survey are consistent with earlier reports that educators are not knowledgeable about TBI and do not feel prepared to manage the range of problems experienced by these students (Cooley & Glang, 1994). In a state-wide survey of 183 educators designed to ascertain educators' knowledge about and perceptions of students with TBI, respondents scored moderately low on a measure of knowledge (mean score was 71%). When these same educators were asked to rate how prepared they felt to meet the needs of students with TBI (on a scale of 1 - 5, 1 = not at all prepared, 5 = very prepared) the average rating was between 2.9 - 3.3, or only "somewhat prepared." Ratings were consistent across behavioral, academic, social, and cognitive domains. As a group, regular educators consistently rated themselves as feeling less competent than did special educators and other consulting and administrative professionals. An interesting finding showed that for this group of educators, knowledge and perceived competence were negatively correlated: those professionals who scored highest on the knowledge quiz reported feeling the least competent.

A second educator survey was conducted in the spring of 1993 in conjunction with a regional workshop on TBI. Thirty-four educators who had experience working with students with TBI completed a questionnaire about their perceptions of the challenges of serving this population. Like the parents surveyed, these educators listed many of the same cognitive deficits identified in the literature as obstacles to success in school for children with TBI. On a scale of 1 - 5 (1 = not descriptive, 5 = very descriptive), respondents rated problems with memory (4.0), attention (4.0), generalization (3.87), problem-solving (3.82), and learning rate (3.76) as being barriers to successful school experiences.

Educators' lack of awareness of the effects of ABI can interfere with effective delivery of services for students (Rosen & Gerring, 1986; Todis & Glang, 1994).

Field notes from classroom observations of one middle school student provide an example:

> *Mike is fully integrated into mainstream classes, receiving support from special education staff. A recent assignment for English, creating a brochure "All About Me," was one that the special education teacher felt was "perfect for Mike," given his artistic ability. He had ample time to work on the brochure in class over a two-week period, and special education assistants and teachers checked with him daily, asking how his project was coming. They were stunned when the day before the project was due, Mike asked one of them, "What are we supposed to do on this project thing?" The special education teacher expressed her dismay: I had been told that students with head injuries sometimes have trouble with 'initiation,' but I guess I didn't understand that meant that he literally would not be able to get going on this without very direct support. Also, when we check in with him, I guess we have to do a lot more than ask, 'How's it going, Mike?' Because he always says 'Fine,' and maybe he really thinks everything is fine. But we need to actually see his work, see what he's done.*

A mother of a fourth grade girl told of how she had asked her child's teacher why she was still adding only single digit figures at school, when at home she had demonstrated more advanced math skills using the computer. The teacher explained that the hospital representative who had conducted a one-hour inservice injury for the staff to ease the girl's transition from hospital to school had told the teacher that it was important for Jane to experience success in her schoolwork. The teacher had interpreted this to mean that Jane should be given only tasks that she already knew how to do. As a result, Jane had received no new instruction in the two years since her return to school.

Results from surveys, focus groups, and qualitative observations suggest that neither educators nor parents are satisfied with the ways students with ABI are served in schools today. Efforts to improve services must include changes on the parts of both educators and parents.

Improving Educational Services: What Educators and Parents Can Do

Few educators have an understanding of the complex and unique issues faced by the growing population of students with ABI (Blosser & DePompei, 1991; Lash

& Scarpino, 1993; Ylvisaker et al., 1991). Acquired brain injury is an under-addressed topic in university teacher training programs; only 8% of graduate programs in Special Education provide training in TBI (Savage, 1985). Clearly, educators can benefit from training in the effects of TBI on the school experience, and in specific strategies for addressing these students' academic, social, and behavioral needs. An increasing number of resources are available to educators to guide staff development efforts in ABI (see, for example, Begali, 1994; Blosser and DePompei, 1994; Savage & Wolcott, 1988; Tyler, 1990). In some areas, state-wide training efforts are being undertaken to increase knowledge and awareness of ABI in school settings (Todis & Glang, 1994; Lash & Scarpino, 1993; Pearson, 1994, Tyler, 1994).

In addition to gaining knowledge about working with students with ABI, educators may benefit from skill development in working collaboratively with the variety of disciplines represented on the school-based team (i.e.; family, related service providers, administrators) to provide educational services in general education settings. Training in creating effective parent-professional partnerships may be especially helpful. Unfortunately, parent-professional relationships can easily become adversarial because of the many stresses both family and school staff face in designing educational programs for students with ABI (Lash & Scarpino, 1993). As educators perceive parents as demanding and overbearing, and parents feel their child's unique needs are not being addressed, parents and teachers create roadblocks to effective service delivery. As Walker (1989) writes:

> "A serious failure occurs in service delivery when the two most influential agents for change in the child's learning experience--parents and teachers--do not collaborate successfully in the planning and monitoring of the child's educational program. When this happens, the essential connection between home and school is lost. Unresolved conflict often leads to severed communication or adversarial encounters, and produces a great deal of stress for many parents and teachers. Ultimately, both parties may feel ineffective in their efforts on the child's behalf, and the student is cheated of the benefit of a coordinated learning experience." (p. 103)

The most effective approach to creating a successful transition back to school and an effective educational program will involve cooperative problem solving with the education and rehabilitation teams, family, and student.

Parents' role. Parents will be most successful in accessing effective educational services for their child when they: 1) are knowledgeable about their child's needs and the types of services that will benefit their child, 2) work collaboratively with school personnel to incorporate these services into the educational program, and 3) take time for themselves so that they can take on the time-consuming and stressful role of being their child's advocate. The final section of this chapter offers guidelines to help parents work with school personnel to create educational plans that meet their child's needs.

Parent Skill #1: Get informed about services that will help your child and about your rights in accessing these services.

Because most educators lack training in ABI, parents may be the most knowledgeable source of information about the effects of ABI and strategies for assisting students to be successful in school settings (DePompei & Blosser, 1987, 1994). Through their experiences in the rehabilitation setting, networking with other parents, and dealing with a variety of professionals in the field of brain injury, most parents learn a great deal about their child's needs and approaches that can be helpful. Parents may also have access to written materials and resources via state Head Injury Foundations, conferences, and other parent groups. Parents are also the most obvious source of information specific to their child's needs (DePompei & Blosser, 1991; Ylvisaker, Szekeres, Henry, Sullivan, & Wheeler, 1987). They can provide suggestions for behavioral, social, and cognitive interventions that are invaluable to the educational team.

Before a child returns to school following a brain injury, parents should insure that an inservice about ABI is provided to *all* staff (including non-educational staff such as janitors, coaches, and bus drivers). Possible sources for presenters include a neighboring district that has worked with students with ABI, a rehabilitation unit, the state Department of Education, or an intermediate education unit or agency. Parents and the student may also want to participate in the inservice, to discuss specifics about the student's injury and needs. As part of the inservice, parents should suggest that their child's school acquire print and

video resources about ABI so they can have resources for ideas and help as needed (see above sources).

> *Jane's mother was closely involved in her daughter's hospital rehabilitation program and was impressed with Jane's ability to process new information when presented on a personal computer. When their small community asked how they could help after Jane was released from the hospital, her mother indicated that she would need a computer to do her homework. The community held a fund-raiser and purchased a computer and software for Jane. When school personnel expressed reservations about Jane's ability to use the computer, and about the value giving sophisticated equipment to a low-functioning third grader, Jane's mother invited several teachers to her home to see how Jane used the computer to practice math and reading.*

One of the most important roles for parents in developing the Individualized Education Plan (IEP) for their child is to share information about ABI with those responsible for providing the child's education. It is therefore critical for parents to become knowledgeable about the IEP process and other school procedures that must be followed in accessing special education services. Parents should familiarize themselves with their rights and responsibilities under IDEA (PL 101-476) by contacting the special education division of their state's Department of Education. Most states also have a parent education group about which the special education division should be knowledgeable (these groups have different names in each state, but their role is the same: to assist parents of students with disabilities in accessing appropriate educational services). In addition, because of the rapid changes associated with ABI, it is important that parents request frequent dates for their child's IEP (Savage & Mishkin, 1994). Unless parents participate fully in the IEP process, important strategies may not be included in the educational plan.

> *A mother received notice that her daughter's IEP meeting was scheduled for a date two weeks away. Noting that only 20 minutes were allotted for the meeting, she asked whether she could reschedule when more time was available, since she would like to talk in depth about her daughter's goals, perhaps through a MAPS (a team -based problem-solving process)*

planning session. The school staff responded that ideally they would hold such meetings for every special education student, but time did not permit this, so the staff would have the goals written prior to the meeting, and the mother could just sign off, as she had in previous years. The mother sought the advice of a parent advocacy group and learned that parents are entitled to be involved in goal setting, that the meeting must be scheduled at a time that is convenient for parents, and that parents are not obligated to sign an IEP just because the school staff is on a tight schedule.

Parent Skill #2: Establish a collaborative relationship

Becoming knowledgeable about effective strategies and services and the mechanisms for incorporating them into the IEP is necessary but does not guarantee that the desired student outcomes will be achieved. Parents must also advocate effectively and work collaboratively with the education team. For many parents, this is a difficult task.

There are a number of reasons why parent-professional relationships become unproductive. Turnbull and Turnbull (1986) list the following factors as contributing to adversarial relationships between parents of children with disabilities and educators: 1) poor communication skills; 2) unfavorable attitudes; 3) parental disinterest and lack of experience in dealing with medical and educational systems; 4) lack of coordination among various professionals and agencies working with families; 5) lack of professional training for dealing effectively with parent concerns and emotions; and 6) logistical problems in arranging contacts between parents and educators.

Improving parent-professional relationships may be less difficult than it seems. Walker (1989) offers three simple skills parents can use to foster collaboration between parents and professionals:

1. **Take the perspective of the educator: understand the position taken by another and appreciate the good intentions that motivate behavior.** It is especially important for parents to acknowledge that teachers and other school staff are already frustrated with the lack of time and resources to accomplish all they need to do.

2. **Appreciate the steps taken that are helpful to parent and child: express appreciation for behaviors in others that are pleasing.**

3. Maintaining frequent contact: sustain communication between home and school through notes, phone calls, and personal visits. Parents may want to find a key person at the school with whom they can communicate regularly. This might be a teacher, counselor, or nurse. Many parents also find it helpful to set up a daily journal in which they and their child's teachers can communicate back and forth from home and school, and to establish a regularly scheduled time to visit with their child's teacher about their child's progress (e.g., a weekly phone call on Friday afternoons, coffee together every other Wednesday morning).

Walker (1989) found that when parents and teachers both used these skills, there were increases in the number and length of parent-professional contacts, and the frequency with which individualized contacts occurred. Parent-professional contacts were also rated as more positive in tone, and there was an increase in positive perceptions toward collaboration in planning services for children.

Parent Skill #3: Remember to take care of yourself

It is important for parents to remember to take care of themselves as they deal with the stresses of working with educators to plan services for their child. If parents don't monitor their own stress and take steps to nurture themselves, they will be less effective advocates for their child (see Singer, this volume). For some parents, this may involve seeking the counsel of friends or a minister, while for others it may mean sticking to an exercise regime. For still other parents, taking time out for a shopping trip and lunch out may be helpful. It may also be important for parents to occasionally take a break from being an advocate and step back and re-group before beginning to advocate anew.

Sometimes parents are frustrated when they attempt to work collaboratively with school personnel but find that the school is unwilling to view parents as partners or team members. Parents may sense that school staff devalue their perceptions of their students' abilities and sees the parents' attempts to give input on school decisions and practices as interference with the educators' role.

Some parents respond by giving up and keeping quiet about their ideas for improving their child's educational program. Other parents develop personal

and practical skills for becoming effective advocates for their children. One mother tells of how this process unfolded for her:

> I came from an alcoholic, abusive family. Before I was forced to begin advocating for my children eleven years ago, I had a high school education and I lacked the self confidence to confront people in authority about getting the services they were entitled to. I gradually became more empowered. But I've never done any of this alone. I've always taken a support person with me to meetings: a friend, my mother, and later, my attorney. My children have great school programs now, and I'm a different person. I'm starting law school next year.

Conclusion

According to those with the most at stake in successful school experiences for students with ABI--parents, educators, and students-- the current educational service system is not meeting the complex needs of this group of students. To improve the way educational services are designed and implemented, educators and parents must work together to create innovative ways to serve children.

This chapter has focused primarily on what *parents* can do to improve their child's educational program: become knowledgeable about ABI and learn to work collaboratively with school personnel so that parents can effectively advocate for their child. The most compelling reason for parents to become effective advocates is the effect of positive parent-professional relationships on the child's school experiences. When teachers and parents work collaboratively, the child benefits.

The experiences of one adolescent serve as an example of the importance of parent advocacy. Following his severe brain injury, this high school senior was determined to carry on as if nothing had happened. Although he experience severe headaches and fatigue, he insisted on trying to maintain a full academic schedule. When he became exhausted and frustrated, he started cutting classes. In an interview several years following his injury, the young man talked about how he needed his mother to be a strong advocate because he was seen by school personnel as lacking credibility.

> When you are by yourself you can't prove yourself and that's why I needed my mom so much. You know, she came in and said "Look? this is what's

going on. ...He's not skipping class because he's a slacker. He's skipping class because he doesn't understand. Because he can't understand. And because he is overwhelmed and it's snowballed and you need to give him some leeway on that." After my head injury...advocating for myself... was really really hard.

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